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Iliac Artery Endofibrosis

Robert J. Hinchliffe

The investigation and management of peripheral arterial diseases in elderly patients, frequently with multiple co-morbidities, are familiar to all vascular surgeons. These patients are often at high risk of limb loss and premature death and intervention is easy to justify. In fact vascular techniques have advanced rapidly to meet the challenges in this population and it is now possible to offer medical therapies and interventions to preserve life and limb even in the most elderly and frail patients.

Vascular disease in younger patients, especially those who are elite athletes represents a different challenge. Healthcare professionals including physical therapists and doctors in primary care and sports medicine rarely manage conditions such as iliac artery endofibrosis. Most vascular surgeons infrequently manage the condition. Patients presenting to a vascular surgeon with suspected iliac artery endofibrosis often do so against this backdrop of delay or failure to suspect or diagnose vascular disease. Consequently patients frequently present late with persistent and frequently debilitating. They are often frustrated by their symptoms and impaired athletic performance and have been investigated extensively by an inter-disciplinary group of healthcare professionals usually focussing on musculoskeletal pathology. They may have seen neurologists and even psychologists.

Most athletes experience minor injuries from which they make a rapid and full recovery. Therefore the expectations of these young people and those associated with their welfare is high. Invariably they expect a rapid and perfect solution with early return to competitive sport. For many it is unfathomable that they may have a career threatening disease.

The indications and outcomes of vascular interventions in younger patients are concerning because they remain largely uncharted territory. The effectiveness of vascular surgery in preventing amputation and death is difficult to dispute in older patients with advanced disease. However, its effectiveness in restoring perfect health and improving athletic performance remains to be established. The demands placed on a vascular surgical reconstruction in an athlete far outweigh any that might be considered necessary or normal for most patients within the realms of standard clinical practice. And the durability of any surgical repair will, perhaps be required for half a century or more. These factors undoubtedly

explain why many vascular surgeons feel a certain reluctance to offer surgery to the youngest patients with mild or moderate (in many instances only haemodynamically significant under the most severe exercise load) vascular disease unless there is clear evidence that the underlying disease process is likely to be life or limb threatening.

Published data on the outcomes of surgical intervention in the short term are sparse and almost non-existent beyond 5 years (1). There have even been reports of deaths and major (limb threatening) complications following surgery. And yet there appear to be an increasing number of patients being offered surgery. For patients there are clearly a number of complex motives not least financial ones for professional athletes. But given the requirements and demands placed on vascular reconstructions it is hard to understand why any sensible vascular surgeon would recommend vascular reconstruction for a young otherwise perfectly healthy person with iliac artery endofibrosis.

There are some reasons why iliac artery endofibrosis appear to be increasing. Cycling in particular is a booming sport with increasing participation with high training loads and extreme aerodynamic cycling positions may play a role. There is an increasing awareness of the problem especially among the professional peloton. The detection rate may also be increasing in those presenting to vascular surgeons following attempts have been made to standardise (non-invasive) diagnostic algorithms to detect the disease in specialist units (2, 3). The true incidence especially in elite athletes may just be a lot higher than previously recognised with haemodynamic evidence of endofibrosis in some 10-20% of elite athletes (4). And there is some suggestion that surgeons have become more liberal in their indications for surgery. This may be consequent to observations of progression of endofibrotic disease in those who continue athletic activity and a smattering of reports of acute limb ischaemia due to dissection and occlusion of external iliac arteries (1, 5). Preliminary outcome data from specialist units appear encouraging with few serious complications and most athletes appearing to resume competitive sport (6, 7).

There are difficulties for surgeons and patients alike in that there appear to be no viable alternatives to relieve symptoms other than exercise cessation or surgery. Conservative therapies such as the use of biomechanics and physiotherapy appear to be largely ineffective and interventions that may prove useful for peripheral artery disease due to atherosclerosis such as supervised exercise therapy and angioplasty / stenting are either ineffective or contra-indicated. For many exercise cessation is the most reasonable management strategy.

Persuading elite athletes and more surprisingly ‘weekend warriors’ that this is the most sensible decision should not be underestimated and may be extremely difficult. Others may wish to continue to exercise if their symptoms are stable.

Until recently efforts to understand iliac artery endofibrosis have been limited to a handful of specialist centres who have reported on their own diagnostic algorithms and surgical outcomes (3, 8). The INSITE Group have performed a consensus study on the current diagnosis and management of iliac endofibrosis (9). This is a useful first step to draw together some of the disparate opinions on the diagnosis, natural history and management of the condition. However, much remains to be done if we are going to standardise the overall management of the condition and therefore improve patient outcomes and prevent unnecessary patient harm and improve outcomes. Key issues include delineating the natural history of the disease and identifying those at highest risk of developing the condition and particularly its complications.

A disease registry for patients with iliac endofibrosis will prove invaluable to patients and surgeons alike. It is no longer acceptable to operate on patients and fail to record their outcomes for external scrutiny and the promotion of clinical research. The use of these sorts of registers has greatly improved our understanding of a number of other rare diseases (10). And in some cases it has also been possible to perform randomised trials.

For elite cyclists and triathletes in particular, iliac artery endofibrosis could be considered to amount to an occupational disease. And therefore both athletes and their governing bodies should consider the wider impact of the disease on their sport and members. Both groups have an important role to play in promoting and contributing to research in the field. Only with the support of athletes, the medical teams that manage them and governing bodies will it be possible to perform the necessary clinical research to improve care.

Perhaps it is time for vascular surgeons to look to the example set in sports cardiology. Sudden cardiac deaths are shocking in young athletes. These experiences have galvanised the sporting community to work with cardiologists to generate the necessary research to identify those at highest risk of sudden death and develop methods to mitigate the risk. Few would dispute the progress that has been made in sports cardiology including the delivery of national cardiac screening programs. These advances could be replicated in peripheral arterial diseases.

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